

Improving Care of Dying Children

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Every year about 5,000 children aged 0 to 14 years need hospice care in the United States. Children seem to know that they are dying, although this is difficult for parents to accept. Clear, empathic understanding is needed. Communication with clarity and understanding is imperative with the changes in goals from cure to palliation to comfort. The ideal place for most dying children is at home, where symptoms can be managed as effectively as in a hospital.

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There are three possible treatment goals for children. Cure is the first goal. When cure is no longer possible, palliation is next. When dying is not immediate and the quality of a child's life is still good, procedures and medications may prolong that life. We will speak to the third goal, when comfort becomes the highest priority and the prolongation of dying is to be the only likely result of aggressive treatment. Comfort care is not euthanasia. Withdrawing procedures that have no benefit for a child is not euthanasia. Cure-oriented treatment can be futile. A dying child may actually live longer in a home environment than in a hospital.

Clinical Issues in Terminal Care

Do Children Know They Are Dying?

Many investigators have provided the research base that changed the clinical practice of physicians, nurses, and other health care professionals caring for gravely ill children.2-4 Their studies gave evidence that, indeed, children do know when they are dying. Some of the possible reasons that a child would know this are the loss of ambulation, energy, and enthusiasm; awareness of feelings and actions of others; the depression that may be sensed; and resting without feeling rested. Based on clinical experience, children seem to be more aware of physiologic changes in their bodies than are adults. Treatments have become increasingly complex, however; in fact, some treatments for certain cancers bring children close to death and then "rescue" them. Some children make amazing recoveries from the point of near death due to serious toxicity or complications of treatments, all of which make dying and the death event more difficult to predict.

How Many Children Die Per Year and Why Do They Die?

About 45,000 children aged 0 to 14 years die each year. We have estimated that 5,000 will need clinical

hospice services⁵; Table 1 shows the conditions of 4,115 children who died in 1992 for whom such services might have been desirable.⁶ According to the National Hospice Organization, 90% of hospices accept children, and about 1% of the 246,000 who die in a hospice or with hospice services at home are children, which is roughly half of the estimated population need (*National Hospice Organization Newsline*, October 1993; 3:1-2). There are about 35,000 infant deaths in the first year of life; it is uncertain how many would be eligible or appropriate for hospice clinical services.

What Should Be Done When Cure-Oriented Treatment Is Stopped?

Good communication between a health care team and parents and children is always important but becomes crucial when a child is terminally ill. At that point, health care professionals need to objectively step back and realize that a cure is no longer possible and that any further intervention will only have an adverse effect on a child's remaining time. They must then be able to communicate this to parents and the child. In an atmosphere of open communication, parents are encouraged to ask questions about treatments. It is the health care team's responsibility to make sure that parents understand what they are told. It is particularly important for physicians and nurses to listen to the child and other family members and to understand a family's concerns and priorities when attempting to shift the focus of care from cure to symptom control. Anger at health care professionals because they "gave up" and regrets or guilt based on misunderstandings are difficult to resolve after a child has died and may be barriers to resolving feelings around the death. Parents and family members must be able to look back and have a sense of peace because they "did the right things."

For most families, the decision to stop cure-oriented treatment for a child with terminal illness is usually made

Age and Possible Hospice Care	Cancer, Leukemia	Congenital Anomalies	Heart DIsease	Pneumonia and Influenza	Human Immuno- deficiency Virus	COPD	Accidents	Homicide	Suicide	Total
Aged 1-4 yr										
Possible hospice care	479	856	286	188	161					1,970
hospice care							2,467			2,467
Aged 5-14 yr Possible hospice										
care	1,105	448	284	104	104	100				2,145
hospice care							3,388	587	314	4,289
Total		1,304	570	292	265	100	5,855	587	314	10,87

by the physician, with parental involvement at some level. Families should ask, "What are the goals for future treatment?" Whether to stop cure-oriented treatment is a major responsibility for health care professionals, and openness and willingness to discuss this difficult subject are imperative. Families should be encouraged to ask about the wisdom of continuing cure-oriented treatment whenever they have questions. I believe that families are requiring more information in this area than is usually given. When health care professionals do not handle this decision responsibly, the tragedies can be many.

The major communication difficulty between families and health care professionals occurs when the goals of treatment change from cure to palliative care. Physicians may think they have informed the family of the impending death and that cure-oriented treatment is no longer the goal, but the family may not understand the full import of the message. Technical language is a frequent barrier to understanding, as is physicians' unwillingness to repeat information and answer questions. A primary care nurse may have a role in these conversations in reaffirming the information that the physician has shared and ensuring that consistent information is given.

Dealing with the family during the final stages of a child's life is one of the most difficult situations that health care professionals find themselves in. Unfortunately, because of the nature of medical technology, health professionals may at times find themselves prolonging death rather than improving the quality of life. Health care professionals have an obligation to the families of patients to be honest and objective about their child's condition, treatment, and prognosis. This includes telling the family when it appears that further therapy is simply prolonging the child's dying, thus continuing and possibly increasing suffering.

Conversely, the meanings of such treatments as the use of steroids or irradiation for comfort rather than cure need to be made clear. It is imperative for parents and family members to understand that the goal of these treatments is for comfort care.

Although experimental therapies should be made available when appropriate, parents should not be made to feel obligated to commit their child to research protocols. The first obligation of health care is "to do no harm."

Where Should a Child Die?

No child should have to live unnecessarily in a hospital. A number of research studies demonstrate that most terminally ill children, as well as their families, do better when the child is cared for at home. The importance of parental attachment and nurturing of children must not be put aside because a child is dying. Facing the end of a child's life, families must be able to make the most of each moment together. The successful provision of home or hospice care for children does not occur without careful planning, however. Effective nursing case management, either through the hospital or the home care and hospice agency, can aid a smooth transition from hospital to home. Communication among the various health care professionals is extremely important and is often facilitated by a nurse. The child's and family's individual needs must be considered in discharge planning and in providing education and support for parents or other caregivers at home. Hospice care and other related services such as respite care are essential for most parents, but may not be covered by medical benefits or may not be available where they live. In some areas there are agencies dedicated to providing bereavement support and counseling for families of children with terminal illness. A nurse can help families to take advantage of such local community resources.

The physicians and primary nurses who have been the principal caregivers should try to stay involved with families and help make a smooth transition from hospital to home and hospice care. Hospice services are increasingly available throughout the country. With assistance and support by the personnel in the treatment centers, local community-based hospices or home care agencies can be immensely valuable in assisting families of dying children. Where hospices are not locally avail-

able, nurses with medical and nursing support from pediatric specialty treatment centers can assist a family.

What About Reimbursement?

Home care is effective in reducing the total costs of health care. But the economics of health care in this country have resulted in a lack of stable funding of home care for children. The funding for services varies among health care professionals and from state to state. Even when hospice care and other related services are covered by state Medicaid programs or private carriers, there may be no mechanism for helping parents access these services. If such services as 24-hour-a-day on-call nursing, respite care, and durable medical equipment for home use are not covered, the cost of these essential services may prohibit families from taking advantage of the basic hospice services that are covered.

Most parents would prefer to care for their children at home despite the tremendous amount of energy and time that is required. Because of economic problems, many children with cancer and other terminal illness live out their lives in hospitals, at great emotional cost to themselves and their families. In one study, the costs of hospital care were from 22% to 207% more than home care.1 The variation in comparisons depends on regarding home care as an alternative to inpatient hospital care or a larger concept of care that included added services at a time when a child would not need hospital care.1 More recent data have been reported from the Children's Hospital in Los Angeles on provider use and duration in a pediatric hospice program for 177 children retrospectively and for the families of 27 children prospectively enrolled in a pediatric hospice program. The mean total cost for the families was \$4,808 per patient; incidental expenses were \$446 and indirect costs \$1,478 (indirect costs include foregone earnings of the family, friends, or volunteers). These researchers concluded that children can be cared for at home whether or not they use hospital outpatient or intermittent inpatient care and whether or not they continue with aggressive therapy. They also showed that services can be made available to both single- and two-parent households from a wide variety of socioeconomic backgrounds. In another study, the median cost for children who died at home was \$4,858 compared with \$13,975 for children under traditional care.10

Managing Symptoms at Home

The best use of pain medication and compassionate concern for the physical, psychological, and spiritual well-being of a child and family should be the primary foci of the professionals caring for a dying child. Goals of treatment should be for the child to function to the maximal level of ability: being with the family, riding a bicycle, going to the grocery store, or attending school, as the condition permits and the child desires.

Pain. Although it is known that children experience the same degree of pain as adults, children are still frequently undermedicated for pain. Successful pain management involves 24-hour dosing, with "rescue dosing" as part of the treatment plan. Morphine, the most commonly used pain control medication, can be given by mouth, suppository, or through self-regulating intravenous infusion pumps. With the new infusion pumps by catheter, full pain control is possible with patient-controlled analgesia. Rarely is hospital admission essential for pain control, except for surgical blocks. Generally parents can be taught to provide pain medication.

The provision of adequate analgesia should not be confused with the intentional termination of life. Adequate pain control is essential for the quality of a child's last days of life. There is no evidence that adequate pain control shortens a child's life. Adequate attention and resources need to be directed to the humane and competent treatment of pain and suffering in all children.

Because most pain medications, especially narcotics, lead to constipation, the prevention of constipation is a requirement. This can be done by the concurrent administration of a laxative such as docusate calcium (dioctyl sodium sulfosuccinate; Colace), glycerin, or bisacodyl (Dulcolax) suppositories. All of these methods are used successfully with young children at home.

Nausea and vomiting. Nausea and vomiting can be more difficult to control than pain; however, these symptoms are less common. When they occur, they can cause substantial discomfort for children and families. Ondansetron hydrochloride, a serotonin-receptor blocker, is most effective. 11(p61)

Sleeplessness. It is imperative for a child to sleep at night so that the parents also receive some rest. Drugs such as diphenhydramine hydrochloride (Benadryl), chloral hydrate, phenobarbital sodium, or diazepam (Valium) are effective.

First-aid measures. Families can be taught how to handle nosebleeds, seizures, diarrhea, and other predictable clinical problems. For stopping bleeding, either pressure or ice pack may be used over the bleeding area. The nose may be packed with an absorbable gelatin sponge (Gelfoam) or clean gauze. Most seizures can be controlled by administering medications such as phenytoin (Dilantin), phenobarbital, or diazepam. The patient's head should be turned to the side to keep the airway open. Efforts must be made to control all symptoms.

Parental anxiety. For parents who decide to use home-based hospice care, the anxieties associated with taking a terminally ill child home may be great. Most parents have not even considered the possibility of home care. Identified fears of families caring for a dying child include the unknown, abandonment by care providers, not being able to control symptoms, and thoughts associated with the child's dying at home.¹²

There is much about dying and death the family may not even consider, such as contacting a funeral home, whom they wish to notify of the death, how to tell the children at school, and effects on siblings. A hospice or home care nurse should gently counsel parents about these practical matters so they can be better prepared. At this point of care, there should be no emergencies that require admission to a hospital. There is no longer any reason to call 911. If parents panic, they should be instructed to call a hospice or home care nurse. The coroner should be notified so that the death is not treated as a police case.

Unique Family Issues

Making Life More Meaningful Before Death and Bereavement

What is most important for this child and family? Some families celebrate an early Christmas or birthday. Other families need help with financial and other practical problems to be able to turn their attention to making the remaining time with their child meaningful. When a child dies, parents and siblings need those memories.

Reactions of Siblings

The ages of siblings and what they have been told and understand about the situation add great variability to response patterns and make generalizations difficult. Neglect and jealousy may be the most common. Siblings, especially younger ones, may feel neglected when attention is given to a dying child. They also may need reassurance that they are not responsible for the death of the child. Including siblings in helping to provide some of the care for the dying child may be useful, but the siblings need to be given time and space to acknowledge the difficulty of seeing their sibling so ill and the deterioration that occurs as death approaches. Removing a sibling from the home during the dying process should be avoided, if possible. Bringing in additional help may be more useful for all the family members. Children's concept of death is based on their developmental level and their own experiences. If a young child is removed from the situation, it may be more difficult for that child to understand and resolve the loss of a sibling. In a nine-year follow-up, most siblings said the experience matured them, and no more than one of five had long-term negative responses to the death of a sibling.13

What Is Death Like?

For parents caring for their dying child, uncertainty about what occurs at the moment of death is a major cause of fear. Most families have not witnessed a death, especially in their home. They do not have the clinical knowledge or experiences to know what to expect or even which questions to ask. Parents and other members want to ask but often do not even know how to ask. Therefore, physicians and nurses should speak to the specific details of the impending death, gently and sensitively taking into account the cultural background and level of knowledge of the family.

Symptoms that may occur during the actual time of dying and of death need to be described clearly. For example, 80% of a sample of children gradually and peacefully stopped breathing as they died.14 The remaining 20% of children may have difficulty in breathing for the last few seconds or minutes, which is agonizing for parents to

watch and extremely frightening for a conscious child. Dyspnea should be relieved with morphine. Propping the child up in bed can help relieve air hunger. Although erratic breathing (Cheyne-Stokes respirations) should be explained to the parents, no treatment needs to be given because the child is unconscious and therefore most likely not suffering. If there is rattle during breathing from increased secretions in the posterior pharynx, low-dose atropine sulfate can be given. Rarely will there be hemorrhaging. If there is any possibility for hemorrhage, the family needs to make the necessary preparations, such as having red washcloths or towels readily available.

Health care professionals should never abandon a dying patient. The telephone is an important tool in providing access to the families by the health care professionals they have learned to trust and who they depend on. A phone call can also allay the health care professionals' worries about the family members. Phone calls will be greatly appreciated.

A telephone is a key component in maintaining good symptom control. A nurse on a home visit can assess the situation and notify the child's physician, and medications can be ordered from the local pharmacy; in this manner, symptoms can be managed relatively easily.

"Do-not-resuscitate" orders for a dying child should be agreed on and understood by the family. Parents who have been prepared for the death may suddenly request resuscitation. At this critical time, resuscitation should not be done. The parents need to be gently reminded that resuscitation would only be prolonging dying and, in fact, would or could cause harm to their child. Parents may not be prepared for their emotional response to terminal symptoms. As noted earlier, many hospice agencies request that parents call their 24-hour line, not 911. The presence of a hospice team member can help parents appreciate the value of a peaceful passage at the time of death. The child needs to be respected. The parents should not feel guilty because cardiopulmonary resuscitation was withheld if they understand its futility in this context. The memory of a resuscitation attempt is usually a negative one.

Most parents will want to be present at the time of the death of their child. Holding and talking to the child during the last few minutes of their child's life can provide precious memories afterwards. To encourage the parents to tell their child at such a time that they love him or her seems so simple, but parents are not sure how to deal with a dying child. The death of a child is relatively rare in today's society. Encouraging a family then to spend some time with their dead child is important. Some parents may need time to acknowledge the death of their child, to let go and say good-bye.

There should be no need for a coroner's involvement in the expected death of a child at home. A physician or hospice or home care nurse should contact the coroner's office and inform them of the presence of a dying child in the home and provide the coroner with the name of the involved physician. A funeral home may be called when the family is ready for them to come. A few families may wish to take their child to the funeral home. This needs to be cleared, as some states do not allow a dead body to cross county lines. Some parents will wash and put clean clothes on their child. Allow for various activities as families will differ in what they wish to do. 15-18 It is important to be sensitive and supportive to what is meaningful to the family.

Bereavement Issues

Part of every physician's and nurse's responsibility is to give empathic support and guidance for bereavement. A health care team should be involved in careful planning before death. Referrals should be made if a physician or nurse is unable to meet the family's needs. Individual clergy, social workers, nurses, and physicians and such groups as Candlelighters, Compassionate Friends, and church members can help. Professional referrals are available for assistance from psychologists, psychiatric social workers, and nurses. Bereavement can be different for persons in the same family. Three styles of grieving were identified: "Getting over it," "Filling the emptiness," and "Keeping the connection."19 Bereavement may take longer than anyone would expect. A common worry is of being insane with the feelings and emotions that a bereaved member may have.

Research done on bereavement concerned long-term parental bereavement patterns, persistent guilt, and ongoing grief.8 The findings indicated that home hospice care for terminally ill children resulted in a more satisfactory resolution of parental grief on a long-term basis than death in a hospital.

Conclusion

Good communication by the health care team with the family is essential in the transitions from the goal of cure to palliation and finally to comfort. Dying children and their families need to be given the option of home care. Health care supports are necessary. Good symptom management, especially pain control, is feasible in the home. The dying process and care of the body following death need to be explained to the family. Relationships need to be established with local hospices. At the policy level, sufficient reimbursement needs to be established.

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